

Family Partnership Newsletter



MISSOURI DEPARTMENT OF HEALTH AND SENIOR SERVICES

HEALTH.MO.GOV/FAMILYPARTNERSHIP

Taking a Break When You Need Help

Breaks are important for both you and your child! But taking a break can be difficult for parents, especially when you have a child with special needs.

Caring for a child, whether special needs or not, can be mentally, physically and emotionally challenging and exhausting. Recharge your body and your mind! Taking a break is important to your mental and physical well-being. It can increase productivity, reduce stress, and better your relationship with your family. Here are some solutions that can benefit you, your child and your family:

- Build time into each day so that you can take care of your mind and body. This includes time to shower, exercise, prepare and eat healthy foods. Plan ahead so that your spouse, another family member, or paid caregiver can be available for your child during this time.
- Use a paid caregiver or another family member when you need to run errands. This allows you to get things done quicker and not worry about your child's needs during this time.
- Once a month, try to get out of the house with your spouse or a friend to maintain relationships and have adult conversation.
- Breaks or short get-a ways may look different during the COVID-19 pandemic if safety is a concern. Instead of going out to a restaurant, you may plan a meal outside or go to a park when the weather is nice.
- Have several trusted respite providers trained, if possible, so that if an emergent need arises or you just really need a mental health break, you

have someone already prepared and comfortable caring for your child. This also ensures your child is familiar and comfortable with the caregiver.

- Sometimes the best break is a nap. If you can find a quiet place in your home while you have help, take advantage of it!
- Have realistic expectations! Sometimes a break is vital and you need to take it while help is available. We can be tempted to use the time to clean, do laundry, run errands but sometimes we need rest and relaxation more than anything else!
- Go on a nature hike.
- Set up and go on a scavenger hunt.
- Do an at home facial, manicure, or pedicure.



2021 Family Partnership Parent and Caregiver Retreat Announcement

On behalf of Family Partnership, we would like to inform you that due to the continuation of the COVID-19 pandemic, we are unable to host our annual Parent and Caregiver Retreat in 2021. While we will miss seeing you all in person, we feel this is the safest option for all involved at this time. We look forward to hosting an even better experience for all our families in 2022. If you need any assistance, please contact your Family Partner. We hope you all stay safe and thank you for your continued understanding!

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Missouri COVID-19 Update

Missouri continues to battle against COVID-19 transmission with one of the highest new case rates in the nation. As of August 11, statewide we are seeing over 2,000 new cases per day and nearly 2.6 Missourians (42.3% of the total population) have completed vaccination. Experts say at least 70% - 80% of people, need immunity to provide the best chance of minimizing spread within a community.*

Throughout COVID-19, DHSS has collaborated with the CDC and local partners to address COVID-19. The Delta variant is a force to be reckoned with. It is substantially more transmissible – 60 percent more transmissible than the Alpha variant (B.1.1.7) that was first discovered in the United Kingdom.

The Delta variant continues to have an impact in our state. The positivity rate in Missouri has increased in recent weeks as well as COVID hospitalizations. DHSS has been working to produce an information resource specific for local areas in and around current COVID ‘hot spots’. The advisories give current information on increasing rates and the value of vaccination as the best way to stop the spread of COVID-19. The advisories can be found at <https://health.mo.gov/covid-hotspots>. **Covid Stops Here** (<https://mochamber.com/covidstopshere/>), a new campaign launched by the Missouri Chamber of Commerce and Industry, recognizes Missouri workplaces that have achieved widespread vaccination. Checkout the businesses and organizations who are currently participating at <https://mochamber.com/covidstopshere/>.

As you gather with friends and family and return to work, school, and other activities, please take adequate precautions to reduce the risk of this highly transmissible variant. The primary target for the Delta variant and others is unvaccinated individuals. Recent data from the U.K. have shown the mRNA vaccines can be used to fight back against the Delta variant. In fact, data show that when it comes to the Delta variant specifically, the mRNA vaccines developed for COVID-19 were shown to be nearly 90% effective against symptomatic disease and 96% effective against hospitalization. Learn more about the Delta variant from Missouri’s State Epidemiologist at <https://www.youtube.com/watch?v=lVeTPII3-Ak>.

COVID-19 vaccine is widely available and can be found by going to MOStopsCovid.com or VaccineFinder.org. Get trusted facts on the vaccines at MOStopsCovid.com. Getting vaccinated is important for not only protecting yourself, but for protecting those around

you. Missouri recently launched a statewide COVID-19 vaccination incentive program, MO VIP, to encourage vaccination among all Missourians age 12 and up. Over the next three months, 900 Missourians who have or will choose to be vaccinated will win cash or education savings account prizes in the amount of \$10,000. Additional details and registration can be found at MOStopsCovid.com/win.

Thank you to the nearly 2.6 million Missourians who have been vaccinated. If you choose not to get vaccinated, please be mindful of those around you and take these important public health steps:

- Social distancing of no less than six feet;
- Wearing a mask when appropriate;
- Avoiding others that appear to be sick;
- Avoiding others if you are demonstrating COVID symptoms;
- Cough or sneeze into your elbow or a tissues; and
- Wash your hands.

DHSS continues to work with partnering agencies to provide free testing throughout Missouri. To find a testing site go to <https://health.mo.gov/> or call the COVID hotline at 877-435-8411.

For the latest information follow us on [Facebook](#) and [Twitter](#) @HealthyLivingMo.



- The vaccine is the best way to stop the spread of COVID-19.
- Everyone 12 years of age and older is now eligible to get a COVID-19 vaccination.

Get Vaccinated!
COVID-19 Vaccines are Widely Available.



Taking a Break When You Don't Have Help

- Give yourself permission to take 5-10 minutes each day strictly for yourself. This may be hard to do but your children need you to do this. It may require some creativity to make it happen!
- Do something that relaxes you (a cup of coffee, read a few pages from a book, or just sit and do nothing).
- Exercise with children-Put your child(ren) in their strollers or wheelchairs if needed and take a walk. Everyone will benefit from the change of scenery and you'll feel more energized. You can also try including your children in other types of exercise.
- Exercise without children-If you can get even 10 minutes of time to yourself, cardiovascular exercise, gentle stretching or another type of exercise you enjoy can also be helpful and give you a break.
- Practicing mindfulness-This can help reduce your stress especially when breaks are rare. Search on Google for "mindfulness" or find an app that you can use to implement this into your day.
- Have a support system-It really helps to connect with other parents who "get it". Connect with others who have a child with similar needs through local support groups or social media groups. Virtual and online activities may be much more accessible too if you don't have childcare or for safety reasons during the COVID-19 pandemic.
- Special Toys/Shows etc. Have a box of toys that your child(ren) only get to play with once in a while. This will keep them busy for you to take a mini break. Your mini break could be staring out the window, taking a soak (if your child needs close supervision let them play near the bathroom with the door open so you can still keep an eye on them).
- If your child is non-mobile and it is safe to leave alone in a room for a small period of time, do it. Step outside for 5 minutes or so to take deep breaths. (A baby monitor can help you keep an ear out for anything or even the kind with a camera. There are cheap cameras that you can purchase and watch from an app on your phone.)
- Nap time-Take a nap or do yoga during your child(ren)'s nap time.
- Get up before or stay up a little after your child.
- Set up a scavenger hunt and help the family participate in it.
- Go to a State Nature Center (most are free and accessible).
- Sometimes the only "break" you might be able to get is just a few minutes. Make sure the kids are safe. Take a walk to the mailbox to check the mail or just enjoy the fresh air and being outside.

The above list was created in part by using the following resources:

The Center for Parenting Education- SURVIVAL TIPS FOR SPECIAL NEEDS PARENTS... YOU'RE NOT ALONE, I PROMISE!

<https://centerforparentingeducation.org/library-of-articles/focus-parents/survival-tips-for-special-needs-parents-youre-not-alone-i-promise/>

Taking Care of YOU: Self-Care for Family Caregivers: <https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/>

How Mindfulness Can Help Caregivers-Child Mind Institute: <https://childmind.org/article/how-mindfulness-can-help-caregivers/>

Support for Parents of Kids with Special Needs-KidsHealth from Nemours: <https://kidshealth.org/en/parents/parents-support.html>

Planning Ahead When you

These tips can help make your trip more enjoyable for the whole family.

- Call ahead to your hotel and let them know you are traveling with a child who has special needs and explain any accommodations you may need such as a room on the first floor, close to pool, room for a wheelchair, etc. We have often gotten better rooms by calling and booking over the phone versus booking online.
- If you will be staying for an extended period of time and your child requires oxygen, talk to your DME supplier to see if they can contact another supplier near where you are going/staying and have supplies for the time period delivered there. Or, work with the hotel and have the supplies shipped to them and make sure they have arrived before you leave for your trip.
- Make a spreadsheet of all needed medical supplies for the amount of time you will be traveling.
- Make a vacation binder with a spreadsheet planning your trip. Include phone numbers to all doctors on your care team and a medication list. Make a care schedule for medical routines such as feeds, medications, or care that has a designated



time to maximize your vacation. Map out all local hospitals in that area in case an emergency were to arise. Have an emergency medical bag handy with all supplies and a few days' worth of medications and/or medical equipment.

- Research all the places you plan to visit and follow up with phone calls to check for accessibility and make other requests as needed.
- Be Flexible! (This one is hard!) Not everyone understands what it is like to travel with a child that has additional needs and not every place will be equipped for your child. Educating kindly goes a long way.
- Carry a doctor's note with your child's diagnosis and limitations in case a park requires documentation or you go to an unexpected location that may require it.
- Missouri's Disability Portal has some great information about traveling. Visit their webpage at <https://disability.mo.gov/leisure.htm>.

For information on Missouri Medical Home, check out the brochure developed by the Family Partners at <https://health.mo.gov/living/families/shcn/familypartnership/pdf/FamilyFormsManual.pdf>.

Other Ideas When You are Traveling

Accessible Playgrounds in Missouri: <https://www.accessibleplayground.net/united-states/missouri/>

Accessible nature/trails in the United States: <https://www.accessiblenature.info/>

Accessible nature/trails in Missouri: https://www.accessiblenature.info/?page_id=216

Wheelchair friendly trails in Missouri: <https://www.alltrails.com/us/missouri/ada>

Missouri Department of Conservation free activities: <https://mdc.mo.gov/events-s3>

Best Missouri Special Needs Camps Directory: <https://bestspecialneedscamps.com/best-missouri-special-needs-camps.html>

Looking for family, accessible, or unisex bathrooms? Check out: <https://americanrestroom.org/restroom-locations/>

Check out your local library as they may have a summer reading program in which "readers" get prizes etc.

Maintaining Your Dignity — in Public

Hear from our readers:

- Having an older child in diapers is difficult. The changing tables in most public restrooms are too small and I have concerns as to cleanliness. Thinking of using the bathroom floor is also not an option. I usually seek out a spot that is isolated and change my child's diaper in the wheelchair which tilted back to make it easier. Other times I carried an outdoor blanket that was waterproof on one side. I always made sure the waterproof side was on the floor when I changed my son. Then I would carefully fold the blanket so that the "good" side was folded into itself before putting it back into its storage bag. As soon as we got home I would wash the blanket and storage bag.
- If we were at an amusement park or another venue that had a first aid station, I would take my child there to change him. They have first aid beds that they sanitize after each patient and they have curtains around each bed.
- Humor.... Using humor is always good.
- Our daughter can stand, so sometimes we change her while standing in a bathroom setting. I've also taken a vinyl tablecloth and sewed it in half to

make a long mat. I am able to sanitize this easily when we have to lay her down. We also change her in the back of our van with the doors closed.

- I also think about dignity when she is at the doctor, hospital, and other places. We treat her like any other person. We encourage people to talk to HER and ask HER questions. She is non-verbal and will not respond, but she will often smile or take the persons hand. When she is at an appointment or hospital stay and we need to change her or the doctor needs to exam her, we ask her and tell her what is happening. She is much more comfortable with what is going on when she is involved in the task or appointment.
- My son is 13 years old and requires assistance using the bathroom, but only wants to use men's or family bathrooms. If my husband is not with me and there isn't a family bathroom, I call into the bathroom to see if it is clear. If it is, I go in with him and assist him with his needs. If there is someone else around, I ask them to stand outside to inform others that there is a Mom in there assisting.

HUMOR... Using humor is always good.

We Want to Hear
From You!

The Family Partners want to know what YOU would like included in future editions of the newsletter. Please take a few minutes to share your thoughts and complete the brief online survey at https://missouriwic.iad1.qualtrics.com/jfe/form/SV_395j64UxNMxxc0e.

Back to School



While many schools are going back to in-person learning, many children with special health care needs and their families are debating if in-person or remote learning is best for their child. Below is a list of resources to help you make the best decision for you and your family.

- Back to School Tips for Kids with Special Healthcare Needs
<https://www.childserve.org/back-to-school-tips/>
- Making Decisions about Children Attending In-person School During the COVID-19 Pandemic: Information for Parents, Guardians, and Caregivers
<https://www.cdc.gov/coronavirus/2019-ncov/community/schools-childcare/decision-tool.html>
- Remote Learning Resources for Deaf and Hard of Hearing
https://www.decibelsfoundation.org/what_we_do/remote-learning-resources.html



The Missouri Family Partnership strives to enhance the lives of individuals and families impacted by special health care needs, providing resources and information to empower families to live a good life.

Family Partners link together the ability to discover, connect, and network with Missouri families to create a strong support system.

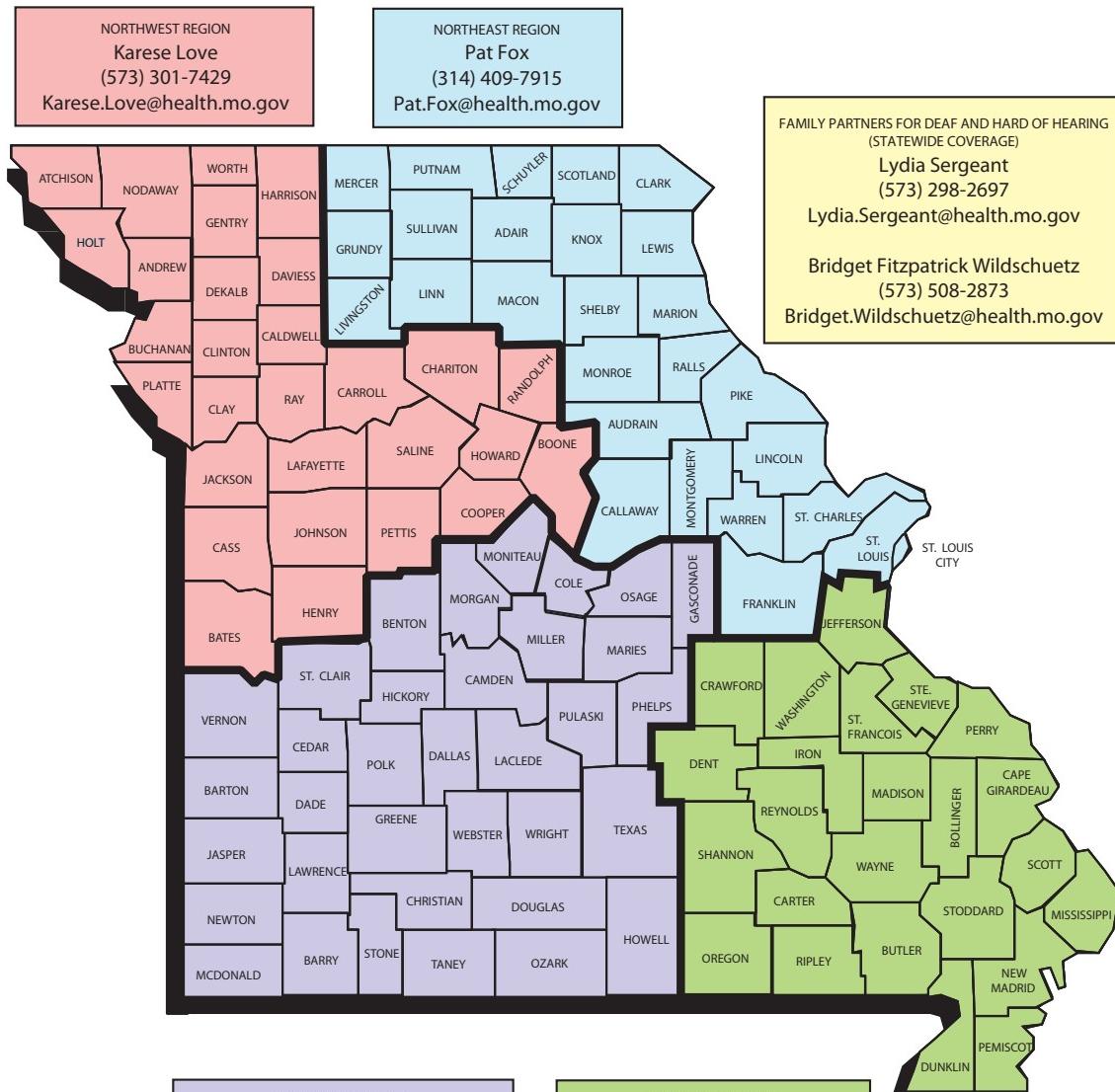


Siblings of children with special health care needs or who are deaf or hard of hearing experience joys and challenges related to their siblings throughout their lives. This webinar provides some insight from siblings of children with CHARGE Syndrome.

Our Journey Together: Siblings Sharing Their Perspectives-CHARGE Syndrome Foundation Webinar:

<https://tinyurl.com/4863jzan>

If you need help finding resources, your Family Partner is here for you!
 See the map to find your Family Partner or call our toll free number 1-800-451-0669.



Missouri Department of Health and Senior Services
 Bureau of Special Health Care Needs
 PO Box 570
 Jefferson City, MO 65102
 1-800-451-0669
health.mo.gov

An EO/AE employer: Services provided on a nondiscriminatory basis.
 Individuals who are deaf, hard-of-hearing, or have a speech disability can dial 711 or 1-800-735-2966.

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